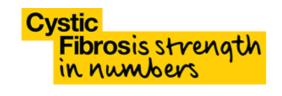
Staging / Pre-production

User: kieran.earlam@cysticfibrosis.org.uk



UK CF Registry

Demographics

a. Surname of patient at birth (if different) 1.4. Forename of patient 1.5. Middle name of patient 1.6. Gender of patient Male Female Age 1.7. Enter DOB DD/MM/YYYY 1.8. Ethnicity of patient White (British) Asian (Other) White (Irish) Mixed (White and Black Caribbean) White (Other) Mixed (White and Black African) Black (Caribbean) Asian) Black (Caribbean) Mixed (White and Asian) Black (Caribbean) Mixed (Other)		ers are locked annually by the Regist ecysticfibrosis.org.uk	ry team as part of the rep	orting cycle. If	you require	a record to b	e edited pl	ease contact
1. Patient Information 2. Genotyping 3. Diagnosis CONSENT 1.1. Has a valid UK CF Registry consent form been signed and dated for this patient? 1.2. Upload a scanned copy of the consent form (optional) Choose File No file chosen Upload Not available PATIENT INFORMATION Basic information 1.3. Surname of patient a. Surname of patient 1.5. Middle name of patient 1.6. Gender of patient Age 1.7. Enter DOB DDIMMYYYY 1.8. Ethnicity of patient White (British) Asian (Other) Mixed (White and Black Caribbean) White (Other) Mixed (White and Black African) Mixed (White and Black Caribbean) Mixed (White and Black Caribbean) Mixed (White and Black African) Black (Caribbean) Mixed (White and Black African) Black (Caribbean) Mixed (White and Black African) Black (Caribbean) Mixed (White and Black African) Mixed (White and Black African) Mixed (White and Black African) Mixed (White and Sian) Mixed (White and Sian) Mixed (White and Sian) Mixed (White and Sian)	Print	Mark as transferred						
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(Caribbean) Asian) \(\bigcirc \text{Black (African)} \times \text{Mixed (Other)} \)							ite and	
				(Caribl	oean)	Asian)		
Black (Other) Other (Chinese)								

Other (Any other ethnic

group)

Asian (Indian)

		Asian (Pakistani) Prefer not to say	
		Asian Not known (Bangladeshi)	
	i. If ethnicity is 'Other', please specify		
ID Nu	mbers		
1.9.	NHS number of patient	Not known or not applicable	?
1.10.	CHI number	Not known or not applicable	?
	Registry Team alerted to duplicate NHS/CHI number?	Email sent Email not sent	
Addre	ess Details		
1.11.	Postcode of patient		?
1.12.	Was the patient born in the UK	○ Yes ○ No	?
	a. County of birth	Select	
	i. Other details, please specify		
	b. Birth country	Select	
	i. Other details, please specify		
GP Int	formation		
1.13.	GP postcode	Not known	?
GENO	DTYPING		
2.	Has the patient been genotyped?	○ Yes ○ No	?
2.1.	Date genotyping sample taken	DD/MM/YYYY Not known	?
2.2.	How many mutations have been identified?	Select ▼	?
2.3.	Genetic mutation 1 (Legacy Protein cDNA)	Select	?
	a. Genetic mutation 1 specify		
	Mutation 1 Poly-T tract		
	■ 5T	9T Not known/Not applicable	
2.4.	Genetic mutation 2 (Legacy Protein cDNA)	Select	?
	a. Genetic mutation 2 specify		E X
	Mutation 2 Poly-T tract		
	□ 5T □ 7T	□ 9T □ Not known/Not applicable	
2.5.	Genetic mutation 3 (Legacy Protein cDNA)	Select	?
	a. Genetic mutation 3 specify		
	Mutation 3 Poly-T tract		
	■ 5T ■ 7T	9T Not known/Not applicable	

BIRI	HWEIGHT				
3.0.	Birthweigh	t		(kg) Not known	?
DIAG	NOSIS				
3.1.	Date of Dia	agnosis			?
	a. Date or pare	diagnosis of CF was conf	irmed with the pat	ient DD/MM/YYYY	
	b. Indic	ate if diagnosis date is ac	curate or estimate	d Estimated Exact	
3.2.	How did th	e patient present with CF	?		?
			Family his	story Genotype	
			Newborn	screening Prenatal / antenatal	
			☐ Not know	n Other	
		r CF associated complica all applicable	tions / signs		?
				Persistent or acute respiratory infection	
				Oedema	
				Electrolyte imbalance	
				Failure to thrive/malnutrition	
				Bronchiectasis	
				Pancreatitis	
				Fertility investigations	
				Liver disease	
				Meconium Ileus	
		How was Meconium Ileus	complication	Surgically	
	n	nanaged?		Medically	
				Not known	
				Nasal polyps	
				Rectal prolapse	
				Steatorrhea/abnormal stools/malabsorbtion	
	lf	f 'Other', please specify			
Diagn	ostic chlorid	e sweat test			
3.3.	How many done?	diagnostic chloride swea	t tests have been	Select ▼	?
		Date		Value	
	Test 1	January 0001	Not known		
		,		(mmol/litre) Not known	
	Test 2	January 0001	Not known		
				(mmol/litre) Not known	
	Test 3	January 0001	Not known		
		,		(mmol/litre)	
	Ta-+ /			Not known	
	Test 4	January 0001	Not known	(mmol/litre)	
				Not known	

5/17/2018 Clinical ALL

Test 5 January 0001 Not known (mmol/litre)

New born screening

3.4.	NBS undertaker	ኅ?

a. If no, why not?

a. NBS Result

i. Suspected - IRT?

ii. Carrier - IRT?

iii. Equivocal - IRT?

iv. Not Suspected - IRT?

b. NBS IRT results

i. Date 1st IRT sample taken

a. IRT result

ii. Date 2nd IRT sample taken

a. IRT result

c. Laboratory Details

i. Which laboratory was the sample sent to?

a. if other,

ii. Date sample sent to Lab

3.5. Referral Details

a. Date patient referred to regional CF team

b. Date patient seen by regional CF centre

c. Date patient seen by local CF centre

○ Yes ○ No

Not known

Born before NBS started

Born outside UK

NBS declined

Appropriate sample not obtained before 8 weeks

Not known

Carrier

Equivocal

Suspected

Not suspected

Not known

Select...

Select...

Select...

Select...

DD/MM/YYYY Not known

(ng/ml or μg/l - mean value)

DD/MM/YYYY Not known Not taken

(ng/ml or μg/l - mean value)

Select...

Not known

DD/MM/YYYY Not known

DD/MM/YYYY Not known

DD/MM/YYYY Not known

DD/MM/YYYY Not known

N/A (not shared care)

Faecal elastase

3.6. Was a diagnostic faecal elastase sample taken?

a. Date of sample

b. Result

○ Yes ○ No

DD/MM/YYYY Not known

(mcg/ml) Not known

OUTCOME

Death

3.7. Has the patient died?	○ Yes ○ No	?
a. Date of death	DD/MM/YYYY	
i. Is date of death an estimate?	○ Yes ○ No	
b. Cause of Death	Select	
If 'Cancer', please specify	Bowel	
	Breast	
	Brain	
	Cervical	
	Liver	
	Lung	
	Lymphoma	
	Oesophageal	
	Ovarian	
	Pancreatic	
	Skin	
	Testicular	
	Other	
Other		
c. ONS Date of Death	01/01/0001 00:00:00	
d. ONS Primary cause of death		
Diagnosis reversal		
3.8. Diagnosis reversed?	○ Yes ○ No	?
a. Diagnosis reversal date	DD/MM/YYYY	
b. Reason for reversal of diagnosis?	Select	
i. If 'Other', please specify		
	Not known	

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